

## **9 Transparency in care: how can public quality reporting help to empower patients? – Viktor Werner**

### ***9.1 Introduction***

The central question in this study is whether enhanced transparency allows an increase in the specific knowledge of one particular group and thereby boosts its power. The new knowledge examined in this case study is the access to public quality reporting (PQR) data by Dutch patients confronted with difficult care choices. PQR describes the practice whereby the information that hospitals collect for their internal quality reporting, is made public.

I would like to highlight that the process of making this information public can be regarded as a form of "transparency inward", another central theme of this volume. In my case the inward transparency consists of providing patients with new insights into the quite complex and therefore often in-transparent institution hospital. For a long time hospitals have been collecting data on the quality of their care in order to monitor the performance of their departments (Faber et al., 2009). After the 2001 "landmark report" from the American Institute of Medicine (IOM) policy-makers all over the world wished to increase the transparency of health care systems for patients (Kurtzman & Jennings, 2008, p.349), so that patients could judge the quality of care in hospitals (Faber et al., 2009). This led to the creation of multiple PQR initiatives. However, as patients were reluctant to use them, they remained rather unsuccessful (Faber et al., 2009).

Starting from the observation that PQR incentives have proven so unsuccessful, the main question of this contribution is how (elective surgery) patients can be encouraged to use public reporting systems to take informed hospital choices. Elective surgery in the medical realm means that the

undertaken medical intervention is not performed in a state of emergency and is planned in advance. This project utilizes "targeted transparency" as a lens to review the functioning of PQR systems in a single case study. I pay particular attention to the challenges patients in the Netherlands face when deciding on a hospital to undergo elective surgery. Understanding the current shortcomings is essential before discussing why more targeted transparency is necessary to empower patients to make active care choices. My main research question, therefore, can also be worded differently: which issues make patients reluctant to use public quality reporting data when choosing a hospital for elective surgery? These issues are apparently not a negligible factor, since patients though valuing the provision of PQR data, frequently refrain from using it (Ketelaar et al., 2014; Magee, Davis & Coulter, 2003). Scholars refer to this as the choice-choosing paradox.

The academic importance of this study is twofold. Firstly, it increases our understanding of the reasons why a considerable choice-choosing paradox persists in the Netherlands. Secondly, on a more conceptual level, it aims to avoid the common oversimplification of transparency in medical care. The current practice all too often equates transparency with providing more information, which is believed to lead automatically to better care choices. However, is not necessarily (targeted) transparency. Two theoretical aspects are important in this respect. Firstly, people are in need of information to take optimal decisions (Bessire, 2005), but the information is only useful (in other words, becomes targeted transparency) when it truly helps individuals to act. Secondly, this form of transparency can effectively change the relationship between doctors and patients, and thereby help decreasing existing power asymmetries (Bessire, 2005).

The societal relevance of this study has three main dimensions. Firstly, if public reporting schemes become widely used, they could increase societal welfare. They promise to increase active consumer choice, which pressures

hospitals to strive for higher output quality, which in turn could increase patient satisfaction and safety (Audet et al., 2008). Furthermore, patient satisfaction is markedly higher when doctors are taking care decisions jointly with their patient rather than acting in an authoritarian way (Ong et al, 1995). PQR information could help to make such shared decision-making easier. This in turn could help to reverse the trend of doctors' alienation from their patients, which Shorter (1991) has identified. Secondly, the unintended consequences of the underlying principal agent dilemma could be reduced if patients were empowered with data on the quality of care to make informed care choices. Thirdly, governments invested heavily on PQR schemes and returns have been marginal (Victoor et al., 2012). Understanding and avoiding the persistent difficulties are the keys to unlocking the desired returns on investment.

## *9.2 Introducing the Dutch PQR Scheme*

This section provides background on the Dutch PQR system to familiarize the reader with the case study. In the Dutch context scholars speak of comparative performance information (CPI) given to patients. The availability of CPI data has been greatly enhanced through the Healthcare Market Regulation Act (HMRA) in 2006. This law requires hospitals to provide the necessary data to feed healthcare quality databanks (Ketelaar et al., 2014). The data includes patient conditions related to structure, process, and patient outcomes, and is monitored by the "Nederlandse Zorgautoriteit" (NZA, translated as Netherlands Health Care Authority) (Maarse & Paulus, 2011).

The three concepts (structure, process, and patient outcomes) are part of Donabedian's long established framework to measure the quality of care (Wong, 2002). Care structure refers to basic information on the

configuration of a hospital (for instance ratio of doctors per patient). The term process refers to provision of information on the type of treatments or surgery offered to patients with a specific disposition. Outcome is concerned with what happens to a patient. This can be the occurrence of complications in form of infections. Or it can also concern data on the patient's satisfaction with the hospital (Raleigh & Foot, 2010). The information on structure, process and outcomes in Dutch hospitals is used by external actors to create a ranking of all Dutch hospitals, which are publicly accessible on the internet (Ketelaar et al., 2014). Taking an active choice is facilitated by the fact that most Dutch citizens live in proximity to several hospitals (Centraal Bureau voor de Statistiek, 2014). Two additional factors that often influence the hospital choice of Dutch patients should be mentioned. Firstly, that General Practitioners (GP) are functioning as gatekeepers for care and second that health insurers are required to cover a patient's full hospital cost (Enthoven & van de Ven, 2007).

The main instrument for the implementation of the HMRA are public and private websites aimed at informing patients, as for instance [kiesBeter.nl](http://kiesBeter.nl) or [Independer.nl](http://Independer.nl) (Dixon, Robertson & Bal, 2010). Before 2006 comparative quality data was scarce. In the past GPs mostly advised their patients to opt for the hospital they had the closest ties with (Dixon, Robertson & Bal, 2010). Today, the role of GPs is different, as they are meant to empower patients to choose health-care providers according to their quality (Berg et al., 2005) and degree of need satisfaction (Maarse & Paulus, 2011). Empowerment is accomplished when patients do not only actively choose a hospital, but also make this choice based on all necessary information. The term "necessary information" refers to the amount of information enabling patients to take an as rational decision as possible.<sup>1</sup>

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<sup>1</sup> I use the concept of *bounded rationality*, it entails that "even in the presence of seemingly objective information, individuals are prone to a host of cognitive distortion" that leads them

### 9.3 Methodology

The literature on patient choice shows that the persistence of so called "care-path dependency" in many cases means that patients see no opportunity and/or necessity to take an active hospital choice (Victoor et al., 2014)<sup>2</sup>. Ketelaar et al. (2014) introduced an elegant way to surpass the limiting effects of care-path dependency by focusing on elective surgery, since in this case patients are strongly incentivized to take an active choice. This insight of Ketelaar and colleagues was gratefully incorporated into this paper. Therefore, it was decided to focus on PQR information handed to patients undergoing elective surgical intervention.

Gaining insight into the current difficulties of the PQR systems is important to answer the research question. It needs to be asked in what way patients are deterred from actively choosing a hospital, before substantial changes to current systems can be made. In the literature review five countries with highly developed PQR schemes have been identified. The choice for the Netherlands is motivated by three main considerations: Firstly, in the United States, no nationwide PQR scheme exists, and patient choice is often limited through issues with health insurers that have special arrangements with particular hospitals (Audet et al., 2008). Secondly, Canada and Australia have been excluded as both nations are sparsely populated, which often disables active hospital choices (Morris & Zelmer, 2005; O'Connor et al., 2007). Thirdly, the UK has a PQR system that was created in reaction to a medical scandal. The extension of the PQR regime to

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to take decisions which are different from what could be expected in a "world of perfect rationality" (Fung, Graham & Weil, 2007, p.33). Therefore empowerment of patients is referring to enabling patients to take *bounded rational* decisions.

<sup>2</sup>Care-path dependency entails that normally patients remain with the same set of doctors, and do not reconsider their choice once new conditions emerge (Victoor et al., 2014).

the entire National Healthcare System (NHS) was only justifiable by policy-makers under the pretext of inducing cost efficiency and waiting time reduction gains through more active patients' choice. Patient empowerment, in other words, was not the focus in the UK (Dixon, Robertson & Bal, 2010).

#### *9.4 Gaps in Existing Research*

This section provides a short overview of issues around PQR that have been discussed in previous studies. Thereafter, I explain how this study, by adopting a new perspective on PQR, contributes to the existing literature. So far a number of studies have been concerned with the underlying motivations behind PQR schemes and possible benefits (Duke et al., 2014; Raleigh & Foot, 2010; Colmers, 2007; Fotaki et al., 2008). Additionally, many scholars have described promising ways to design highly functional PQR systems (Chen et al., 2014; Morris & Zelmer, 2005; Faber et al., 2009; Tu & Lauer, 2009). In general (regardless of country) scholars regularly pointed towards the three counts on which PQR schemes are held accountable on: improved quality of care (Marshall & McLoughlin, 2010; Colmers, 2007; Vrangbaek et al., 2012; Kroneman, Maarse, & Van der Zee, 2006; Fung et al., 2008), higher cost efficiency (Ikkersheim & Koolman, 2012; Vrangbaek et al., 2012; Dixon, Robertson & Bal, 2010; Rademakers et al., 2014; Robertson & Burge, 2011) and empowerment of patients (Magee, Davis & Coulter, 2003; Fasolo et al., 2010; Victoor et al., 2012). Although positive side-effects of PQR systems have been discussed, too little attention was given to the empowerment of patients. In contrast to most previous studies, this study focuses on possibilities to empower patients to take active choices, in particular by bringing in the concept of targeted transparency taken from Fung, Graham & Weil's book "Full Disclosure" (2007). Many scholars have invested a lot of time and effort into assessing

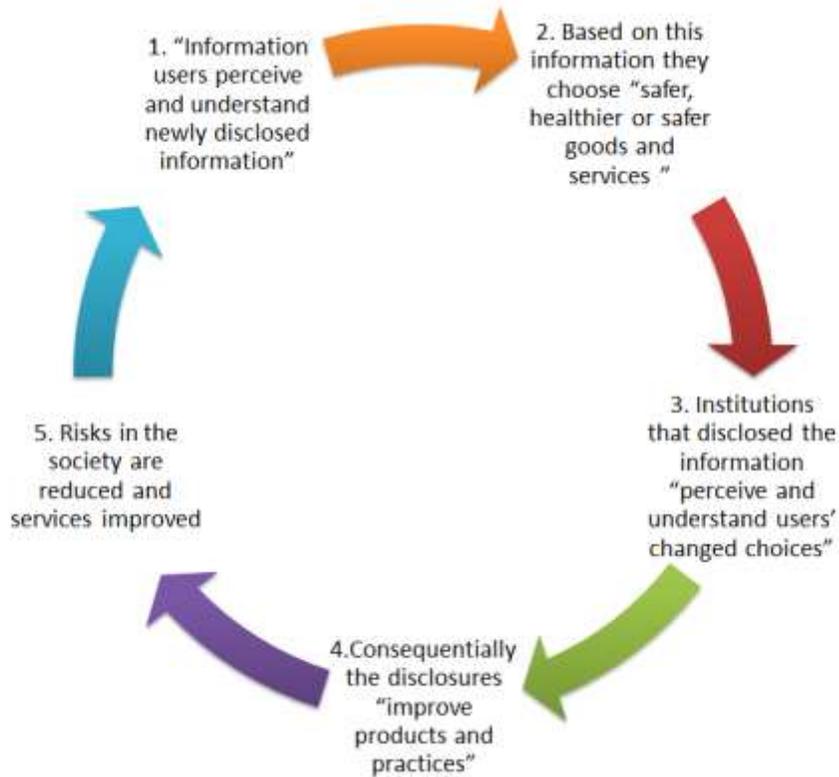
whether and how patients in the Netherlands are using PQR tools with interviews (Dijs-Elsinga et al., 2010; Damman et al., 2009; de Groot et al., 2010; Marang-van de Mheen et al., 2010; Moser et al., 2010; Ketelaar et al., 2014; Victoor et al., 2014). However, all of these contributions only provided, if at all, a discussion of their findings in the light of studies from the USA or the UK. Never were the findings of several papers on the Netherlands combined in one study, as attempted here. What is more, placing the flaws of the PQR systems under scrutiny, with targeted transparency functioning as guiding aid, qualifies us to suggest possible improvements to the functioning of PQR regimes.

### *9.5 Introducing Targeted Transparency to this Study*

Fung, Graham & Weil (2007) differentiate between three different types of transparency policy tools. The oldest transparency tool is "right to know legislation" that became prominent in the 1960s. The second generation of transparency policy tools is "targeted transparency" which "requires disclosure of specific factual information [...] by corporations or other private organisations" (Fung, Graham & Weil, 2007, p.xiii). The third generation of transparency tools is "collaborative policies", which entail that the users' feedback on the way they would like to use disclosed data is incorporated into the government's efforts to administer factual information.

The origin of targeted transparency according to Fung, Graham & Weil (2007) lies in the breakdown of two neoclassical economic paradigms. The first was that perfect information prevails on all markets. Policy-makers became aware that information asymmetries prevail, as some groups have more information on the quality of certain products than others. Health professionals for instance possess much more knowledge about the differences in the quality of care than ordinary citizens. In such a situation

the risk of moral hazard emerges. Providing additional information promises to overcome this situation. Secondly, policy-makers understood that information is not costless to acquire and not equally accessible to all individuals, therefore no completely rational decision can exist. They realized that more information does not automatically lead to more rational choice, as floods of information can increase the cost of using information. The provision of information should, therefore, be tailored to the needs of patients so that they can embed it into their decision process. The disclosure of quality indicators could decrease information asymmetries. Thus, information users would be empowered through functioning targeted transparency regimes to take decisions that reduce societal risks and improve the quality of public services. All targeted transparency tools are believed to resolve problems through the same sequence of events summarized in the "action cycle" (Fung, Graham & Weil, 2007, p.6; Chart 1).



*Chart 1: Displaying the "action cycle", visualisation by author.*

Fung, Graham & Weil developed a framework to assess how effective targeted transparency policy has been and how identified problems can be resolved. The central question in measuring the effectiveness of the PQR regime in the Netherlands is how successful new information has been embedded into the way the intended audience takes decisions. The targeted transparency perspective offers to heighten understanding of the current flaws of the Dutch CPI system. This analysis can help to improve the current design and could allow to eventually empowering citizens.

## *9.6 The Dutch Experience: Problems and Challenges with Public Quality Reporting*

The PQR scheme of the Netherlands has not been as effective as policy-makers originally hoped (Ketelaar et al., 2014). Recent studies find that less than 15% of elective surgery patients make use of PQR for care choices (de Groot et al., 2010; Ketelaar et al., 2014, Victoor et al., 2014). In this section I try to answer the question: Which factors or problems make patients reluctant to use public quality reporting data when choosing a hospital for elective surgery? I suggest five major reasons why elective surgery patients remain reluctant to use CPI.

Firstly, patients, choosing a certain hospital once, are inclined to choose the same hospital again. Moser et al. (2010) found that patients had chosen a hospital they knew, regardless of the quality indicators. Thus the "ultimate point of reference" for patients appears to remain the experience during previous hospital admissions (Moser et al., 2010, p.368). This in some cases stemmed from mistrust and fear of manipulation of CPI. Most often however, no concrete reason was found (ibid.). The major deterrent of using PQR is previous experiences with the local/nearest hospital (Ketelaar et al., 2014). That patients only considered the local hospital could have many other reasons than just the previous experience. It may be relevant for some patients to remain close to their home to ease the access for calls (ibid.). Dijs-Elsinga et al. (2010) found that 40% of those patients who reported that they considered using CPI in future did not plan to actively compare hospitals. This large group of patients would like to check PQR data only after they decided on a hospital, as a means of reassurance (Dijs-Elsinga et al., 2010). Victoor et al. (2014) claim that care path dependency remains the main reason for this behavior. Many surgery patients entered a certain hospital with a condition which required no operation, due to a progression of their disease, however, are prompted to undergo surgery

(ibid.). The care path dependency in these cases persists, as patients want to continue their treatment at the same hospital with the same doctors.

Secondly, a major obstacle to the success of Dutch PQR systems is that patients highly value their personal networks. The PQR only supplements other streams of information. Moser et al. (2010) found that in case of conflict patients always attach greater value to the information they receive from others. Two main groups function as the prime information sources on surgical hospital options, on the one hand GPs, on the other hand friends and relatives. GPs are consulted by 73.7% of those that desire to seek others advice on the choice they have to make (Dijis-Elsinga et al., 2010). Patients often trust the judgement of their GPs greatly and often delegate the decision as they feel that they lack the expertise to evaluate the situation and the quality indicators (Victoor et al., 2014). De Groot et al. (2011) claim that consulting the GP however cannot be seen as major reason for not using CPI. Regarding the role of relatives and friends Moser et al. (2010) found that choosing a hospital is a very personal issue, which around 1/3 of patients decide to discuss with individuals close to them. These patients attach high value to the recommendations they receive and tend to trust them more than PQR data.

Thirdly, the low awareness for the differences in the quality of care appears to be one of the most central elements when one seeks to understand why patients neglect CPI. Dijis-Elsinga et al. (2010) found that only 2.3% of interviewed patients had used information on the number of patients who had faced adverse effects, whereas after the study 38% of patients seemed willing to use this information for future choices. This could be explained by the fact that patients have to become aware of quality of care differences before they can integrate them into their decision making. Victoor et al. (2014) confirmed that patients remain inactive (70.4%) because they are unaware of differences in the quality of care. Moreover he

argues that patients remain inactive as they are satisfied with the prospect being able to switching hospital if deemed necessary. The likelihood to use CPI in general increases vastly with the degree to which patients assume that quality of care differences persist (Ketelaar et al., 2014). Moreover, patients who reported that they had faced adverse effects (compared to those that did not) were most interested in using PQR data in future (Marang-van de Mheen et al., 2010). This suggests that events that make patients question the quality of care can make PQR more salient to their choice. What should be considered however is that adverse effects have been self-reported which invites problems with selection biases. For example patients who are very concerned about their care may be the ones that notice adverse effects and the ones that use CPI at the same time.

Fourthly, that the choice-choosing paradox persists in the Dutch health care sector appears to have two reasons. Firstly, Moser et al. (2010) found that among their interviewees many showed "camouflaged decision" making as they claimed to use PQR data to motivate their choice of hospital, but in reality relied on their personal experience (p.369). The discontinuity between claimed behaviour and practiced behaviour would be a consequence of the wrong perception of the patient's own decisional behaviour. This wrong perception becomes visual in the finding that  $\frac{3}{4}$  of patients who do not compare hospitals claim to have made a deliberate hospital choice (de Groot et al., 2010). Can one really speak of a deliberate choice, if the only thing people appear to have chosen deliberately was not to choose? Secondly, humans only have limited cognitive resources, and thus miss some pieces of information when taking a decision. Patients claim that a vast amount of information and factors are important for their decision process, Yet, Dammann et al. (2009), report that in the end they incorporate only fractions of those factors in their decision making process. The authors suppose that the reason for this is the build-up of the human mind which

can only process 6 pieces of information at a time. Consequently, patients merely tend to scan information, as they are looking for "information they want and in the light of questions they already have in mind" ( p.2).

Fifthly, the usage of aggregated scores appears to be very limited, which makes PQR websites less attractive to patients. Dijs-Elsinga et al. (2010) report that almost  $\frac{1}{5}$  of patients say that they will use PQR systems if they offer one single aggregated measure that helps them to choose a hospital. Independer.nl uses aggregated scores in combination with star ratings whereas kiesBeter.nl does not. Thus, Damman et al. (2009) state that the websites should reflect the human need better to go from generic to more specific information. Because aggregated scores, with an option of a further itemized presentation of information, are most likely to be helpful to patients. Currently they are easily overwhelmed by the abundance of information on Independer.nl and kiesBeter. This can make patients reluctant to use these websites and hence neglect PQR data (Damman et al., 2009).

Next to the five points discussed above, I want to highlight three areas where one might assume that patients struggle with PQR databanks, but evidence shows that they did not. Firstly, one might suspect that patients are just not aware of the existence of CPI. This assumption was found to be incorrect as scholars report that between 60% (de Groot et al., 2011) to 89% (Ketelaar et al., 2014) know where they could find CPI. Moreover, it could be a concern that not every Dutch citizen is computer literate enough to use the provided web tools. This fear can be dismissed as very few patients reported this as the reason for not using CPI (Ketelaar et al., 2014). Such information should nevertheless be seen critical as patients may be ashamed to admit. This also applies to Moser et al.'s (2010) finding that the great majority of patients is able to understand CPI, however does not see how it should help in their decision process.

### 9.6.1 PQR as a Targeted Transparency Tool: Success or Failure?

In the following, I elaborate on the implications of the problems identified in section 9.6.1, for the success of the targeted transparency tool at question. Only if one understands what obstructs the effectiveness of PQR improvements can be made. According to Fung, Graham & Weil (2007), an effective transparency system requires high user-centeredness, which depends on the value potential users attach to information and their capacity to understand the disclosed information. Using Fung, Graham & Weil's (2007) concept of user-centeredness we automatically accept the assumption that patients' decisions are underlying "bounded rationality" (p. 55). Leading us to assume that in reaction to a lack of ability to take optimal decisions, individuals tend towards "good enough decisions" (p. 55). What matters for patients under this assumption is:

1. The perception that the given information has value for achieving their goal  
(choosing an as good as possible hospital)
2. The information's compatibility with their decision making routines
3. The comprehensibility of the information

The first problem already emerges with perceiving the value of the information. It was found that most patients are only to a limited extent aware of the differences in care facilities. Consequently, the information provided on *Independer.nl* appears to be less relevant to patients. Moreover, the value of the disclosed information often remains low as many patients find their "ultimate point" of reference in their own experience. (Moser et al., 2010, p.386). Fung, Graham & Weil (2007) came to the same conclusion in

their study. They report that the value of newly disclosed information remained low in those cases where people tend to rely on their own agency and networks for taking a decision. The authors argue that disclosed information only is used if individuals see a "substantial immediate long-term gain" (p. 56). This could explain the drastic increase Dijs-Elsinga et al. (2010) found after their interviews for the readiness to use information on adverse effects. Furthermore, the value of disclosed information also depends on the cost of attaining it. Patients are currently overwhelmed by the abundance of information on *Independer.nl* and *kiesBeter* (Damman et al., 2009), making it burdensome to attain desired information.

The choice-choosing paradox makes one question the information's value for patients. Does the paradox imply that patients greatly value the idea of receiving CPI, however, tend to not use it to actively compare hospitals? When one recalls that patients tend to look at the PQR data only for the hospital they have already chosen (Dijs-Elsinga et al., 2010), this could indicate that patients value the disclosed information not for enabling them to take an active choice, but to affirm the correctness of their choice. Using disclosed information to affirm own perceptions than helps to satisfy patients' desire for seemingly rational choice. The value of CPI tends to vary between different patient groups, as patients for example see PQR data slightly different depending on whether or not they faced adverse effects in the past (Marang-van de Mheen et al., 2010). However, all studies discussed find that the majority of patients do not use the data although they know that it exists. Therefore, I concluded that the value of PQR data to Dutch patients remains rather low, when it comes to actively taking a hospital choice. Consequently, the goal of the targeted transparency policy remains unattained.

Secondly, the compatibility with the decision making process is another essential aspect of the effectiveness of targeted transparency

policies. Embedding new factual information is only possible when it fits decision routines of patients. Fung, Graham & Weil (2007) line out that the two most important elements for compatibility are: "format and the time and place of availability". The used format is providing quality of care websites with PQR data. As discussed above we can refute the assumption that a lack of computer literacy is a major explanatory factor for the reluctance to use PQR information (Ketelaar et al., 2014). Nevertheless using the format of websites, could be problematic as patients need to make an effort to visit them. Yet it should be noted that Fung, Graham & Weil (2007) consider web based transparency tools as the most flexible, which makes it suitable to very diverse audiences. Moreover, patient's value aggregated measures (Dijis-Elsinga et al., 2010), which means that the current format of *Indepeder.nl* that provides star ratings is commendable. Fung, Graham & Weil (2007) agree that star ratings are one essential factor for the most successful transparency policies. These aggregated measures are in most cases difficult trade-offs between data complexity and simple normative description. Being transparent about possible inaccuracies, in most cases is sufficient to maintain necessary trust of users though (Fung, Graham & Weil, 2007). The majority of patients seem to trust CPI websites, because they offer precise explanations on the methods of data collection (Moser et al., 2010). These findings show that most patients trust the provided web services, which is a good prerequisite for positive developments in future.

Despite patients' acceptance of the offered web tools, the compatibility with their decision-making practice remains limited. Consequently, patients are only theoretically empowered to make more informed care choices. In reality, patients show little awareness of quality differences in care, trust their own information sources more (family, friends or own experience), struggle with information overload on the offered web pages and often only use CPI to confirm their prejudice. Moreover, the

decision making behaviour is consistent with constructed preference theory (Moser et al., 2010). The theory entails that individuals' preference are not pre-given or steady and only form during the decision process. Thus in each specific situation this process is going to evolve differently. This makes preferences difficult to predict (ibid.). Therefore, compatibility strongly varies from case to case. In conclusion this means that the compatibility between the most patient's decision path and CPI is to be considered only moderate.

Thirdly, in the discussion of the value and the compatibility of disclosed information I already touched up on those aspects relevant to the comprehension aspect (being overwhelmed with the data provided on the websites and difficulty of creating aggregated measures). In general, the insights from section 9.6.1 gives little reason to conclude that the comprehensibility is the most problematic aspect of CPI. Nevertheless, it is advisable to question to which extent patients are actually able to understand the data. Maybe the reason why many Dutch patients do not feel willing to use PQR is based on a under- or unreported fear of not being able to understand the data. Recalling that patients always desire to take the best possible decision they may avoid looking at PQR data to avoid possible confusion. They probably fear confusion as it could be linked to the feeling of not having chosen rational. Overall however, I see no reasons to suggest that the Dutch PQR data is not comprehensible. Most patients appear able to understand CPI on hospitals (Moser et al., 2010). Consequentially comprehensibility is judged to be moderate/good.

The table below summarises the discussion on the embeddedness of the PQR data.

Relevance of Information	Low [-]: Ultimate point of reference remains personal experience of the patient, his relatives or friends.
Format of Information	Moderate [~]: Some aggregated scores and more specific information. Web tools with some flexibility. Unfortunately, no alternatives offered to the website.
Timeliness of Information	Timely [+]: Updated regularly by NZa. Available and accessible to all patients before choosing a hospital for surgery.
Location of Information	Fully Public (Internet) [+]: Accessible to great majority in the Netherlands.
Comprehensibility of Information	Low/Moderate [~]: No major reports of comprehension difficulties, although comprehension is difficult to measure due to camouflaged decisions. Many users got lost in the amount of information.
Cost of Information Access for Users	Low/Moderate [~]: Low cost to attain data, however, considerably higher cost to process the information.
Overall User Embeddedness	Low/Moderate [~]: Problems with the value to users disable good/full embeddedness.

The difficulties in the Netherlands to embed PQR into the decision making process, keeps patients from perceiving the disclosed information and they remain reluctant to use it. This suggests that the studied targeted transparency policy is not enabling many patients to take better informed care choices. From this follows, that the action cycle is not functioning as intended. Consequently, the second stage of the action cycle is rarely reached with the current policy design. Seen from the perspective of Fung, Graham & Weil's targeted transparency model, the policy is a failure. In the word of Fung, Graham & Weil (2007): "To be effective...the information they

[disclosers] provide must become an intrinsic part in the routines of users" (p.90). One cannot argue that the newly disclosed information is anywhere near of being an intrinsic part of patient's decision strategy, when only a minority of patients is using CPI.

### *9.7 Improving the performance of the Dutch PQR System*

In this section I develop some tentative recommendations on how the current PQR system in the Netherlands could be optimized. Three main recommendations increasing the embeddedness are presented: Firstly, changing the role GPs are playing; Secondly, finding alternative ways of distributing PQR data; Thirdly, optimizing the design of the CPI websites.

Fung, Graham & Weil (2007) claim that in situations where "users tend to underconsume disclosed data", it often is beneficial to bring in intermediaries. These intermediaries can help to disseminate and interpret the data. When it comes to the Dutch patient's decision process they all have to consult their GP before being referred to the hospital. Therefore, GPs could function as intermediaries. I show in section 9.6.1 that GPs play a key role in advising patients on their care choices. However, de Groot et al. (2010) and Victoor et al. (2014) warn that too much reliance on the GP could have a contrary effect, as many patients probably would start delegating the decision to their GP entirely. This would not lead to more but maybe even less usage of CPI. De Groot et al. (2010) propose that doctors could receive special training on helping patients to access CPI, without encouraging prejudiced decisions towards their favoured hospital. It could, however, be very difficult for GPs if they had to play two roles at a time. On the one hand they are the authority that has to decide whether or not a patient needs surgery, which means they require the patient's full trust. On the other hand they would have to encourage patients to take an active

choice and refrain from extensively intervening into the patient's decision path. This could confuse patients, on the one hand they are expected to trust their GP to the fullest regarding the decision if and if yes what surgery to undergo, on the other hand are not to entrust their GP with choosing a hospital for them. This conflict could be very problematic as it has the potential to undermine a GPs authority.

It would possibly be much more realistic to only motivate GPs to address the issue of care quality differences between hospitals in the personal consultation. As discussed above, scholars have pointed out that the lack of awareness of care differences is among the prime reasons for the neglect of CPI databanks (Ketelaar et al., 2014; de Groot, 2010; Victoor et al., 2014). A discussion between elective surgery patients and their GPs (about differences in hospitals quality of care) promises that patients may ask for certain indicators to use when choosing a hospital. This qualifies patients to approach CPI data very differently as they already have questions they wish to answer. In the context of humans tending towards merely scanning information based on pre-existing questions (Damman et al., 2009), this approach could optimize the decision path of patients. They are more likely to experience CPI databanks as valuable if they wish to see specific questions answered. Therefore, we recommend that GPs should be encouraged to address the potential differences in quality, as this offers patients to reach awareness that they have a choice to make, one with far reaching consequences. According to Fung, Graham & Weil (2007) the perceived value of information by users depends on the awareness of potential long term effects. I recommend that doctors start bringing quality of care differences onto the patient's agenda, however, should refrain from taking the choice for their patient.

Using GPs as intermediaries could also allow improvements in the relationship with their patients. In the recent past, as a consequence of

increasingly high expectations from scientific medicine a fear of alienation of doctors and their patients emerged (Shorter, 1991). These high expectations poison the doctor patient relationship, and thus lead to a fear among doctors to lose control in patient interviews (Fortin et al., 2012). Doctors could be trained to understand patient interviews more as an opportunity for "shared decision making" than an obligation of having to take the optimal choice on their own (Stiggelbout, 2012). The implementation of shared decision making will require a long time, as it requires changes to training guidelines and conflicts with socialisation of doctors, which is quite paternalistic (ibid.). Establishing shared decision making is nevertheless not utopian. We find that among doctors the most important motivation for staying on the job is "the hope of making a real difference in the patient's life" (Smith et al. 2009). Aziz (2009) argues that being fully appreciated by patients requires two things from doctors: high skills and knowledge as a professional and the ability to help the patients' decision making. Alienation appears to be the consequence of an overvaluation of the necessity of the doctor's high skills as professional. Becoming an intermediary of CPI, in contrast, could help GPs to rebalance the role they play again, so that their influence becomes truly appreciated again.

Depending on the amount of resources for a reform of the PQR regime in the Netherlands, policy-makers should assess if other intermediaries need to be established. Unfortunately, no study dealing with PQR for surgery patients addressed alternative routes than the PQR websites. We, therefore, recommend that more research is tailored towards identifying alternative routes of confronting patients with CPI.

Overall, we do not consider this the most important issue for policy-makers. The primary focus should be placed on increasing the direct value of CPI for patients. Most promising for a possible extension of the PQR regime appears to be the improvement of web services offering CPI. Four aspects

could be redesigned to increase the value for surgery patients. Firstly, Moser et al. (2010) proposed that the information disclosed on the websites could be supplemented with much more information on patient outcomes that patient report themselves. The rationale behind their proposal was that patients greatly value the information they received from others in their personal network. To them this also explains why patients trust CPI on [Independer.nl](http://Independer.nl) as it also includes experience reports of other patients. Through these reports patients can extend their network to all other patients that underwent a certain surgery (Moser et al. 2010). Moser et al. seem to have overlooked two major obstacles that limit the usefulness of patient experience reports. Firstly, patients reports can become problematic if they are incomplete or even incorrect. Patients are probably not able to offer a complete account of the medical outcomes they faced. They maybe do not understand some of the complex processes within their own care path. For example a patient who experience a wound infection after surgery and remission could give negative feedback to a hospital or surgeon although the reason for the infection was not following the surgeon's instructions carefully. Secondly, Moser et al. (2010) give an ill-suited example when they argue that just as reviews on electronics help customers, patient report could as well. In contrast to the purchase of a new smartphone patient outcomes can be a very private matter. Many patients could possibly refrain from sharing their experience on delicate details of their treatment.

In defense of Moser et al.'s (2010) proposal it is worthy to note that Fung, Graham & Weil (2007) also speak out in favour of more user ratings. They report that in their experience with targeted transparency policies they clearly find that users value websites that offer opportunities for public participation. Fung, Graham & Weil (2007) argue that incorporating performance based user-ratings strengthens the trust of users. This increase in trust often allows higher embeddedness of information and hereby

increases the value to users. I would nevertheless be careful with patient experience reports for the reasons discussed above. Maybe a standardized format would be most suitable, where patients fill in an experience report together with their GP.

Finally, also customizing CPI data on the quality of care websites could increase their value for patients. Fung, Graham & Weil (2007) claim that the design process of any new web-based tool should start with "analyzing what information users want and their decision making habits" (p.134). In the case of CPI this means that it would be recommendable to incorporate the factors that influence patients' interest in specific PQR items. I recommend that information on: whether or not a patient has been in a certain hospital before, if he already underwent surgery, his personal mobility and the information on possible experiences of adverse effects in the past, are included as possible filters in the search engines of PQR websites. In the studied academic contributions, all these factors have been identified as influential on what sort of information patients desire. These changes should not be implemented without securing that they do not increase the cost of obtaining information on hospitals. An increase in the time patients use to take their decision risks decreasing the value of information. The difficulty here could be concerns over the sensitivity of the personal care history of patients. Some patients are probably not ready to share the details of their personal care history. This limits the effectiveness of offering more customized searches for CPI. Nevertheless I hold that the websites should offer two different types of search functions. Next to the regular search function, which includes zip code and disease, a more detailed search option should be included. In this more detailed search it should be possible to customize and filter information accordingly to the personal care history. The CPI webpages for such a new design approach would have to increase the protection of sensitive data handled on their websites.

## *9.8 Conclusion*

To conclude, I argue that PQR data in the Netherlands has not been an effective targeted transparency policy tool. It can be considered unsuccessful, because CPI has failed to trigger more active patient choice. Looking for possible reasons for this outcome, I asked which problems explain patients' reluctance to use CPI and identified five major explanatory factors: Firstly, patients see no need to use PQR data when they can rely on own experiences with a certain hospital. Secondly, patients who consult external information sources value the information of their GP or friends and relatives considerably more. Thirdly, many patients show little awareness for the differences in the quality of care, which makes them rather passive regarding hospital choice. Fourthly, patients, although claiming that many different factors are important for their choice, end up incorporating very little CPI into their decision routines and are merely scanning information. Possible reasons for this are patients' tendency towards camouflaged decisions, their personal time constraints and their limited cognitive capacities when processing information. Fifthly, currently only *Independer.nl* uses aggregated scores in combination with star ratings. This is problematic as patients desire aggregated scores for their care choices.

The targeted transparency approach helped to highlight that the embeddedness of CPI into the decision making routines remains moderate to low, which indicates that the policy is not user-centred enough. This study produced valuable insights into the persisting difficulties with embedding PQR data in patient's decision making routines. These insights allow us to formulate three tentative recommendations. Firstly, GPs could act as intermediaries for quality of care information. This can help to establish shared decision making and improve the doctor-patient relationship. I would

recommend that GPs are trained to address the differences in quality of care in the patient's consultation, which would enable patients to approach CPI better prepared. Secondly, I argue that the design improvements of CPI websites promises to increase the value of this information source. Outgoing from the Constructed Preference Theory, new filter tools are advisable to allow patients to search CPI databanks more purposefully. However my advice to policy-makers is to carefully consider what implications this could have for the sensitive data handled on PQR websites. The redesign of these web services could also include more experience reports of patients. A standardized format of experience reports that GP and patients fill out conjointly appears advisable. Thirdly, I urge policy-makers to consider alternative pathways to distribute PQR data. I do not feel to be in a position to give advice on which exact method would be most advisable. Consequently, I call for further research into the way patients are taking their care decisions, and what information format is most suitable to these patterns.

Furthermore, one needs to question some of the underlying attributes of PQR systems. This study on elective surgery patients finds that even in circumstances where care path dependencies are low, the Dutch PQR system is ineffective. The action cycle theory of Fung, Graham & Weil (2007) clearly displays how beneficial targeted transparency policies can be. However, the question should be raised in how far attaining a full embeddedness of quality of care information is achievable even when all recommendations made would be implemented. To clarify possible limits of what CPI can and cannot deliver more research is required. Personally, I have to question some of the choices made in this contribution. Choosing a single case study to answer my research question meant that the findings are not easy to generalize. Moreover, neglecting the financial dimension allowed to say more about empowerment of patients, however vastly narrowed the quantity of sources.

Nevertheless, this paper made a valid contribution to literature on empowering patients. Applying the targeted transparency framework helped to display many difficulties regarding the value for patients, and how these possibly could be approached in future. Focusing on the value of the information, I believe, could make the goal -to heighten the level of active choice taking- attainable. It would be wrong, however, to expect that all patients will use PQR systems in future and benefit to the same degree. Despite all possible limitations, I am convinced that it is desirable to make quality indicators a public resource and remain hopeful for the future.